WHEN A CO-WORKER IS LIVING WITH AIDS/HIV

A Guide for the Workplace

Dedicated to the memory of:

ROBERT MCBRIDE

The Gillette Company

Though your life was too short, you changed our lives.

The suggestions in this guide are based on the personal experiences of people with HIV disease and the co-workers, caregivers, and supervisors of people with HIV disease. I particularly want to thank Robert McBride and Bill Donovan of the Gillette Company for their advice, as well as Nick Romania and Nick Costanza of Polaroid Corporation. In addition, I wish to acknowledge the support of Positive Directions, Inc. of Boston, MA.

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The information in this publication is solely for general information and for educational purposes and is not intended to be legal advice. Businesses and individuals should consult an attorney for specific legal advice.

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Introduction

When you learn that a co-worker has AIDS/HIV disease, you may be surprised, saddened, and unsure of what to do. This is a natural reaction. We have learned how to respond to other serious illnesses like cancer, but AIDS/HIV disease presents unique challenges. This guide suggests ways you can respond with hope and sensitivity when working and living with people affected by AIDS/HIV disease.

Each of us is affected by AIDS/HIV disease, even when we don't have the disease, because all of us are, or eventually will be, the co-worker, friend, partner, family member, or caregiver of someone with the disease. We all need to learn about AIDS/HIV disease, and the suggestions included here are based on the personal experiences of people with AIDS/HIV disease and their co-workers.

Sometimes, when we don't know the "right" thing to do, we do nothing at all. Even if you are unsure of what to do when responding to a co-worker affected by AIDS/HIV disease, the best advice is to respond with your heart. Your sincerity will shine through whatever responses you make. Remember, we are all on this journey for the first time. Even if we don't do or say the best thing possible the first time, we can learn from each other in the process.

People living with AIDS/HIV disease want to continue to live their lives, including continuing to work, to the fullest extent possible. They want to do the best job they can; they want to have valued, worthwhile, productive work to do; they want to be seen as healthy people who, like you, may not feel well from time to time; they want to be helpful, not helpless; they want to continue to be your co-worker and friend and to be as fully a member of the workplace as possible; and they want to hope for a future, while coping with the realities of today. You can help by learning the facts about the disease and offering your support.

The term HIV disease will be used here because it includes all phases of the illness caused by the virus, HIV, from infection to the most serious phase, labeled as AIDS.

The following suggestions are helpful to both men and women living with the disease. Co-worker will be referred to as both "he" and "she".

How You Can Respond to a Co-worker with HIV Disease

- The first person someone tells that he has HIV disease is often a co-worker; this may be you. Respond with your heart: "How are you doing?" "How can I be of help?" Think how you would want to be treated if you were ill. And due to the fear surrounding AIDS, realize how much courage it takes for a person with HIV disease to tell even you, a friend, of his or her condition.
- One of the first people that someone tells that he or she has HIV disease is her supervisor. When a worker tells you she has HIV disease, this is a time for empathy, compassion, and reassurance "How can I help?" Steps to take include:
 - Ask him or her if she has seen your workplace's policy on HIV disease. Give her a copy if she has not.

"We must create work environments in which people affected by HIV disease can continue to live useful, productive lives. To do so is not only an act of humanity, it is good, sound business."

I.M. Booth Former Chairman, President, & CEO Polaroid Corporation

- Assure him or her that her condition is confidential unless she chooses to tell others.
- Assure him or her that she will be treated like anyone else with a chronic illness, and that she will continue to have a job.
- Learn as much about HIV disease as you can, and find out about the resources available to you and your co-worker.
- Respect your co-worker's right to privacy. Just as your own medical information is private, so is that of a co-worker with HIV disease. We all have a legal right to privacy in all medical matters. Since there is no risk of catching HIV disease through normal workplace activities, there is no obligation for a co-worker with HIV disease to inform his supervisor or other co-workers. And he has a right to not share this information until and unless he chooses to do so.

If he or she chooses to discuss his condition with you, be willing to listen with empathy and compassion. Do not repeat any information, including that your co-worker has HIV disease, unless he has given you permission to do so.

If you are a supervisor and a worker tells you that he has HIV disease, under most circumstances, you legally cannot tell anyone else, including your supervisor, without your worker's permission. You can seek legal and other advice by describing the situation but not identifying the worker with HIV disease.

■ Learning that a co-worker or a friend has HIV disease can be emotionally difficult for you. Take care of yourself. You may want to take some time to adjust, to talk with a counselor, or to learn more about HIV disease.

You may find that knowledge of your co-worker's condition is hard to bear alone, and you may want to tell someone you trust. Before you do, ask permission of your co-worker.

There are resources that can help you. Be sure to use them. See the list at the end of this guide.

A co-worker may have told other co-workers, but not told you directly, that he or she has HIV disease. If you feel comfortable doing so, take the first step. Acknowledge that you have heard that your co-worker has HIV disease. A simple "I heard you are ill," or "I heard you have HIV disease," can remove the awkwardness for both you and your co-worker.

If another co-worker tells you that someone has HIV disease ask him if he had permission to tell you. If not, say nothing. If so, you might tell your co-worker with HIV disease that you know.

Sometimes when you learn that a co-worker has HIV disease, you may feel angry or hurt because you discover he has known for some time, but he has not told you before. You may feel that he did not trust you enough to tell you before. This is a normal reaction; many people feel this way. Usually people with HIV disease must first spend time accepting the disease themselves. For most people, this may take

"At Houghton Mifflin, we work to provide benefits that improve our employees' work environment and the quality of their lives. As HIV threatens more and more individuals and families, information becomes critical. Education is the only defense we have against the spread of HIV, and I believe companies have both an opportunity and an obligation to educate their workforces about this disease."

Margaret Doherty Senior Vice President, Human Resources Houghton Mifflin Company months or even years. Only then do they feel comfortable telling other people, no matter how close these other people have been to them.

- Some people may react with fear and anger when they learn that a co-worker has HIV disease. Most people will react with concern and compassion, but some people still do not know the facts about AIDS and they may be fearful. One of the most important ways you can help is to be sure that you and your co-workers have factual information about HIV disease and for you to show co-workers, by your own actions, how to respond compassionately to co-workers affected by HIV disease. Steps you can take:
 - Offer your co-workers a copy of this guide or other brochures on HIV disease.
 - Tell them about the resources listed at the end of this guide, or find out about local AIDS education programs where they can get reliable facts.
 - And encourage your workplace to conduct AIDS education for all employees or repeat AIDS education for your work group.
- If you are not absolutely sure that a person has HIV disease, it is best not to say anything about the disease. Do not ask if she has HIV disease. However, if you feel comfortable in doing so, you might tell your co-worker that if anything is troubling her, you are willing to listen or to help.
- If you hear a rumor that a co-worker has HIV disease, it is best to ignore it. Do not repeat it. You may want to be sure that the person who told you the rumor has accurate information about the disease and about your workplace's HIV disease policy. Give him a copy of this guide. Suggest that he can call an AIDS information hotline or talk with your workplace's physician or health care provider.
 - If you are a member of management and you hear about rumors, you can take two steps. First, make it clear that rumors are hurtful and then encourage your co-workers to respect each person's privacy. Second, rumors about HIV disease usually mean that people need more AIDS information; so sponsor AIDS education for your work group.
- Even if a co-worker has told people about her condition, a good rule to follow is not to be the first to tell other co-workers about your co-worker's condition. Allow your co-worker the right to tell others if, and when, she wants to inform them.
- Once a co-worker has told you that he has HIV disease, you are likely to be curious about his condition. First, ask if he wants to discuss his condition. Don't pressure. And be certain that you really want to know how your co-worker is feeling before you ask. Knowing more may be painful for you.
- One question you should never ask of a person with HIV disease is "How did you get it?" Like other illnesses and diseases, it really doesn't matter how a person became infected. What matters is that she has the disease, that she wishes to go on working and living with as much hope and zest as possible, and that she needs your support and empathy.

"It took an enormous amount of energy and stress to hide my HIV status and, in my case, my sexual orientation. Disclosing both to my fellow peers and the corporation was the most liberating thing I had done for myself in my lifetime. It released me from the mental prison I had been living in, and for the first time in my life let me be me. This, in turn, boosted my self-esteem and overall health by letting me channel all that energy into more positive ways, including my work."

Nick Costanza Finance Operations Analyst Polaroid Corporation

- Never refer to a person with HIV disease as a "victim" of AIDS. The word "victim" is offensive to many because it suggests that they are helpless and this increases their emotional stress.
- When some people first learn they have HIV disease they want to tell other people, including supervisors and co-workers, right away. This may be the right decision. But it is usually best for the person to take some time to think about why it is important to tell other people, including a supervisor or co-workers. Whenever a person is deciding to tell others his HIV status, there are three vital questions: "Why now, or when is the best time?" "Why tell this person?" and "How will disclosing his HIV status benefit him?" If your co-worker is considering telling others about his status, you can help by encouraging him to take some time to consider these three questions. Telling others about an HIV status takes bravery and preparation. You also can help by asking him how he would handle different possible reactions and planning how to do so in advance, as well as considering how this information will impact others. Finally, you can help by being sure your co-worker knows his workplace's policies and benefits in regard to HIV disease.
- When a person first learns that she has HIV disease, she may not behave as though she understands that she has a disease. This is a normal emotional reaction after people first learn they have HIV disease. This reaction is called denial. This is the feeling that "this can't be happening to me" which most of us have experienced when we have had a shock. The reaction may last for a while, sometimes months, until she can emotionally accept that she has HIV disease.

If you know of your co-worker's condition, allow her to come to accept her condition at her own pace. But if denying that she has HIV disease is preventing her from doing her job or from getting the right health care, she may want to consider seeking support from professional counseling. For example, many workplaces have Employee Assistance Programs for individual counseling.

- A co-worker with HIV disease may turn to you for support, advice, or help. He may want to vent his anger, or look to you for support about fears and worries, or ask your advice on how to handle issues, such as how to continue work, whether to tell his supervisor or co-workers that he has HIV disease, or when to stop working. Steps you can take:
 - Listen with care. Do not judge. Do not dismiss or minimize fears and concerns; acknowledge them as real and important to him.
 - Help him to get all the facts before making any decisions.
 - Find out what resources are available to him and to you within your workplace and outside.
 - Learn about your workplace's policies and the laws about HIV disease.
 - And learn about HIV disease.
- There are 3 phases of HIV disease, and most people with HIV disease feel it is important for other people to know which phase they are in. Listen carefully to

how your co-worker describes her condition. In the first phase of HIV disease people are infected with HIV but have few or no symptoms of illness. They look and feel fine most or all of the time. People in this phase will say they are "HIV positive, asymptomatic" or just "HIV positive".

In the second phase, people have mild to severe symptoms of illness, and many may be receiving drug treatments during this phase. These people have periods when they look and feel fine and periods when they are ill, sometimes seriously ill. People in this phase will say they are "HIV positive, symptomatic" or just "HIV positive".

The third phase is labeled AIDS, in which people can look and feel well most of the time or be ill for varying periods of time (See Glossary).

Whether from the disease or from drug treatments, most people in the second and third phases of HIV disease do not feel their best much of the time, yet they have the grit and determination to go on living and working, despite HIV disease.

- HIV disease can be unpredictable and rapid changes in a person's health condition are common. One day a co-worker may be fine. The next day, he may be in the hospital with a life-threatening illness, and a short time later he may be back at work. No one knows how sick or healthy he will be from day to day, or how long he will have. The disease's unpredictability makes it difficult for everyone. It is best to be ready for the unexpected and to always act with hope.
- HIV disease and the drug treatments for the disease can cause fluctuations in a person's physical condition and energy level. These fluctuations may be from week to week or day to day or even during the day. For example, the drug treatments can cause nausea in the morning, which often passes later in the day. Or people with HIV disease can get very tired during the day and need to rest or even to lie down. Expect these kinds of physical changes. Flexibility in work hours and work schedules is often helpful.
- Your co-worker may have marks on his skin caused by the illnesses that people with HIV disease develop. For example, she may have purplish blotches caused by Kaposi's Sarcoma, a kind of cancer. A normal reaction to seeing these marks is to be curious. You or others will probably look at the marks or even stare. People with HIV disease tend to be self-conscious. They do not want these marks of illness any more than you would. Try not to stare. If others comment about the marks, help them to become educated about HIV disease and its effects and to respect the dignity of your co-worker, as they would want their own dignity respected if they had an illness.
- Over time, most people with HIV disease lose weight and become thinner, and illness may make them look tired and sick. Most people with HIV disease have times when they look and feel ill, and times when they feel good. Tell your co-worker how good he looks when he does look good, but only if it is realistic. If your co-worker's appearance changes, don't ignore it. Be gentle, yet remember, never lie. However, there is no need to point out negative changes in appearance.

DO SAY things like: "You're looking great!"

DON'T SAY things like: "You're looking thinner. Are you losing weight?"

- HIV disease can cause an emotional roller coaster ride. Having the disease triggers strong feelings, and these usually are normal, emotional reactions. Sometimes your co-worker will feel happy, excited, and energetic. Sometimes your co-worker may be short-tempered or irritable, which may cause problems with other co-workers. Or she may be withdrawn or isolated. She may not join the usual activities with other co-workers as she has done in the past. For example, she may eat alone rather than with co-workers. This too, may cause problems because co-workers may feel rejected. Usually these feelings will pass or diminish over time; sometimes the same feelings return from time to time. If your co-worker thinks that these feelings interfere with her life or work, she may want to consider seeking professional counseling. For example, many workplaces have Employee Assistance Programs. You can help:
 - Be willing to listen and just be there with her.
 - Accept the silences, the desire to be alone, and the anger. Don't take these feelings personally.
 - Reassure your co-worker that the emotions she is having, such as anger, guilt, or sadness are normal.
 - Be patient, and encourage other co-workers to be patient. It takes time to work through strong feelings like anger and sadness, but most people will, with time and with the support of those who care about them.

Whether you are talking to a co-worker with HIV disease or to a co-worker who has lost someone to HIV disease, below are some things to say and not to say:

DO SAY things like this:

"The feelings you have are understandable."

"What help do you need?"

"I'd like to just be with you, if that's all right."

"I don't know what to say, but I care."

DON'T SAY things like:

"Be strong."

"It will be better soon."

"You must get on with your life."

"Wait till I tell you about my illness."

"I know how you feel." (Unless you really have had the same experience.)

People with HIV disease may send you confusing messages about help. Some people have trouble asking for help and try to carry on alone when it would be better to ask for assistance. Some people ask for help and then are angry with you when you give it. Talk with your co-worker about how he feels about asking for help and how he wants to be helped, before he needs the help. The more open this discussion can be, the less frustration and anger there may be.

"I spent two years hiding my illness at work. My pain, depression, and discomfort were misinterpreted by my supervisor as lack of motivation. This caused harmful stress for him and me. Once I revealed my HIV status, I gained respect and understanding from him and my colleagues. The outpouring of support has been incredible, and it certainly has contributed to my long-term survival. I would encourage other people with HIV, or any other serious illness, to consider being open and truthful about their health."

Nicholas Romania Marketing Program Manager Polaroid Corporation

- Even though your co-worker has a serious illness, you do not need to be a punching bag for her feelings. It is easy to feel that you have to "put up with her emotions because she is sick." Though patience and tolerance may need to be emphasized, you do not have to accept all of her behavior. If you do, you may end up angry and resentful yourself, and this will affect your relationship with your co-worker. Describe her behavior to her and let her know how it makes you feel.
- Many people with HIV disease live with fear as much as with the disease. They are fearful of discrimination, of harassment, of losing their jobs, of losing their benefits, and of the reactions of co-workers. They have good reason to be fearful. Many people with HIV disease have been hassled, shunned by co-workers, or illegally fired and denied benefits. None of these things may happen in your workplace, but a person with HIV disease cannot know for sure until he tells those in his workplace that he has HIV disease. So your co-worker may hide his condition. The stress of hiding may harm his health, or he may not go to doctor's appointments because most appointments are during work hours. He may not want to tell the truth about where he is going or lie, so he simply doesn't go to vital medical appointments. Steps you can take if you know your co-worker has HIV disease:
 - Understand and accept your co-worker's fears. Let him work through his fears at his own pace.
 - Help by finding out what your workplace's policy is on AIDS/HIV disease. If your workplace does not have a policy, ask it to develop one.
 - And encourage your workplace to have AIDS education, so those co-workers can respond with compassion and reason because they know the facts about HIV disease.
- Due to fear, some people with HIV disease do not tell their supervisors that they have HIV disease even though their work performance is suffering. Legally, people cannot be fired because they have HIV disease, but they can be fired for poor performance. If your co-worker's performance is declining due to the disease, her best choice may be to tell her supervisor rather than risk dismissal because of poor performance. You can help your co-worker by:
 - Listening and helping to develop a plan on how to tell her supervisor;
 - Explaining the critical need for health insurance and a secure income;
 - Being sure your co-worker knows her legal rights.
 - Offering to join her when she tells her supervisor: and
 - Understanding her fears and being supportive.
- Your co-worker may accept his condition with calmness, sometimes with serenity. This too, is a normal emotional reaction. But do not confuse acceptance of the disease with defeat. Realistic acceptance may free your co-worker from emotional turmoil and give him a sense of power over his life and future.

"When Tom decided the trip to Princeton would be too stressful, Houghton Mifflin gave him a new title and office space within walking distance of our home. There are not too many companies that would make such an accommodation. He took such pride in putting on a suit and walking to the office as often as he could. This gift, as I see it, satisfied Tom's need to keep contributing to

Richard Stote Caregiver/Life Partner

an active force."

the company, and to remain

- People with HIV disease often become more frank and direct in their comments and questions than they have been in the past. Time becomes precious to people with HIV disease. They feel they don't have time to beat around the bush. So, they may become more blunt in asking for what they want, when expressing their feelings, or when discussing work.
- Keep your sense of humor and encourage your co-worker to enjoy her sense of humor. You have heard the saying that "laughter is the best medicine." Sometimes people with illnesses make jokes about their condition. You may be surprised or uncomfortable when they do. Humor can be a healthy way to cope with or to come to terms with something that is painful. If your co-worker sees something funny about her condition, enjoy the joke with her. Be cautious if tempted to joke about her condition in the same way. We may think it is funny to make fun of ourselves, but not so funny when someone makes fun of us. If the joking makes you uncomfortable, then you may want to say that you can understand why she is making jokes about her condition, but it makes you uncomfortable and is it okay if you don't laugh.
- Work often becomes even more important to people with HIV disease after they know about their condition. Work is an important source of self-worth, financial security, including benefits coverage, and provides a sense of stability to many people. Sometimes people with HIV disease work even harder after learning of their condition. Most people, after a time, realize that maintaining their health is as important to them as work is, and they begin to balance the stresses of work with a desire to do what is best for their health. Indeed, enjoying their personal lives often takes on a new importance.
- HIV disease is a legal disability. People with disabilities are entitled by law to reasonable work accommodations, such as shorter work hours or flexible schedules. These accommodations are negotiated between the supervisor and the worker with HIV disease, sometimes with the help of others. Be sure your co-worker knows that he is entitled to work accommodations, and if he asks for advice, you can help your co-worker think about what he needs in order to continue to work and be productive. He may want to have a confidential talk with a lawyer. There are many AIDS service organizations and organizations for people with disabilities provide legal counseling services.
- People with HIV disease may be absent from work unpredictably, frequently, or for long periods of time. This can make getting work done difficult for co-workers. Don't let this go on until you are angry and resentful of your co-worker. Encourage your co-worker to help you and other co-workers to plan your work, so that it can get done smoothly and well, even if your co-worker is absent. A work group in one company, for example, restructured their work, so that the co-worker with HIV disease became the "short-stop" on the work team, filling in for others when they were absent.

■ If you are in the same work group as a co-worker with HIV disease, one way you can help is by assisting to get her work done when she is absent. When absences are sporadic or short, temporarily sharing someone's work can ease the worry for your co-worker and minimize the disruption to your work group. This should be discussed with your co-worker.

If absences are more frequent or longer term, a more formal work plan may be needed that still allows your co-workers to feel as connected and productive as his or her health permits.

- Like everyone, people with HIV disease have good and bad days. On good days, treat your co-workers as you would on any other day. On bad days, treat your co-worker with acceptance and care. Be careful you don't begin to treat your co-worker as someone who is "sick," "helpless," or "dependent."
 - Remember he is an adult and wants to continue his job performance to the best of his capabilities.
- Some people with HIV disease want to quit working too soon and other people go on working too long or too much. There are benefits to continuing to work, such as maintaining income level and social contacts. Also, psychologically, work gives a sense of purpose, which can help emotionally. Physically, working at a reasonable pace helps most people stay healthier longer. So stopping work too soon may not be the best decision. On the other hand, some people work too much or continue to work when it is harming their health. Your co-worker may turn to you for advice about these decisions. Steps you can take:
 - Listen and be supportive.
 - Help her take all the factors into account, including her feelings.
 - Be sure that she uses the resources available to her, such as Human Resource personnel, your workplace's legal advisor and medical staff.
 - Encourage her to discuss this decision with her health care providers.
- Today, most people with HIV disease will be in the workplace for years. In the past, many people did not tell others in the workplace they had HIV disease until they were noticeably ill. Usually, they did not continue to work for very long after this point. Today, people are telling others that they have HIV disease sooner, and with new treatments, people are living longer and healthier lives. This means that many people with HIV disease will be in the workplace for much longer than they have been in the past.
- Focus on and help your co-worker to focus on his capabilities and not his limitations. Over time, people with HIV disease usually are able to do less at work. Nonetheless, emphasize what she can do, while accepting what she can no longer do.
- Treat your co-worker as a healthy person, rather than as a sick person. Expect that he wants to continue to do the best job possible, to take on new projects or a new job, to participate in the social life of your workplace, to be considered for promotions, and to make at least as much of a contribution to your workplace as he always has.

"Growing numbers of people with HIV disease are living longer and are choosing to remain in the workplace, even after an AIDS diagnosis. While the Americans with Disabilities Act has furnished these folks with legal protections to safeguard their jobs, we still have a monumental task to overcome the fears and prejudices of employers and co-workers around the transmission of HIV infection at work."

Jack Smallcombe Executive Director Positive Directions, Inc.

- Support your co-worker in making decisions over which she has control. Illness often causes loss of the control over many aspects of our lives which healthy people take for granted. Even decisions, which appear simple, can be important to the overall feeling of being in control of one's life.
 - One very important area is decisions regarding work, such as work pace and work schedules. Workers with HIV disease can be active partners with supervisors, and sometimes with co-workers, in planning work and work accommodations, as needed.
- Be helpful, but don't "over help". Respect your co-worker's desire to be independent. Doing things for your co-worker who has HIV disease that he can do himself is not the best help. "Over helping", or doing too many things for your co-worker, may lead him to be dependent or feel helpless. Encouraging him to do things for himself, to take charge, to plan, and to think through the challenges of working with HIV disease are some of the best ways you can help. Offer help and let him know he can call on you whenever it is needed. And continue to call on him for help when you need it.
- Because you know a co-worker has HIV disease, you may be tempted to ask her, "How are you doing?" in a tone of voice that means, "How sick are you?" It is tempting to do this every time you see a co-worker. This is a normal expression of concern. However, many people with HIV disease would rather not be reminded over and over again about their condition. The best thing to do is to continue to use the same greetings you have always used with co-workers.
- Include your co-worker in the same work and social activities you always have, whenever possible. Be there for him it instills hope. Be the friend and co-worker you have always been, especially now.
- Have a sincere, positive attitude. Faked happiness is usually easy to recognize. You may be saddened by your co-worker's condition, but for her sake and yours; it is best to be as hopeful and positive as you honestly can be.
- Talk about the future tomorrow, next week, next year. Effective life-sustaining drugs are being discovered which means that people with HIV disease will stay healthier and continue to work longer. It's important to look forward to the future, without denying the reality of today. This includes future work and career plans.
- Touch your co-worker as you always have. A simple handshake, hug, or pat on the back shows you care.
- Make opportunities to celebrate the joyful events in your co-worker's life a new job or promotion, a successful project, birthdays, or a raise, without overdoing special attention.
- Be sure your co-worker knows about any services for people with HIV disease, other serious illnesses, or disabilities offered by your workplace. Also, most local communities have AIDS services, as well. Don't assume your co-worker knows all the options available to him.

- As much as you want to support your co-worker with HIV disease, you may have your own fears and feelings. It is normal to have mixed feelings, both compassion and concerns. HIV disease is a frightening illness, and we have all been given misinformation and incorrect facts. Be sure that you get your questions answered or information you need. Also, talk with people close to you about your own fears and feelings. Just as your co-worker needs you to talk with, you may need someone with whom you can talk.
- Ask your co-worker for her home phone number, the numbers of friends and relatives, or even her physician in case she becomes ill at work, or if she doesn't come to work and hasn't called in.
- Help keep your co-worker from being isolated. This is especially important if his daily contact with the workplace is decreasing or changing. Keep in contact with your co-worker at home by phoning or by visiting if he wishes.
- Some people with HIV disease, due to new treatments, may have remarkable improvements in their health status and may want to return to work even though they have been on disability leave for some time. The worker and his supervisor should know their workplace's policy on disability leaves. Some workplaces, for example, promise that a worker may return to his or her original job, or he may return to a job, but not necessarily his original job. The worker needs to discuss his situation with his supervisor, human resources, and possibly his workplace's legal advisor. Once the worker knows the job to which he will return, he needs to discuss the position and its responsibilities with his supervisor and negotiate any necessary work accommodations.

A back-to-work transition plan is helpful to both the worker and co-workers. For example, the supervisor should announce to the work group that the worker is returning to work and the job he will be performing. The worker's health condition can not be revealed unless the worker has given permission to do so. If he has, it is best to inform co-workers that the person has HIV disease (The worker may want to do this himself.). This allows co-workers the opportunity to have any questions or concerns answered. This may be a time to provide or renew AIDS education. Next, the worker should visit the workgroup and have an opportunity to mix informally with co-workers, perhaps even a back-to-work celebration. Then, there should be a structured schedule for the worker's first day back so that he is smoothly integrated into the work group. Some time after his return, there may be a need for a work group meeting to address any concerns and to answer any questions that arise. In the first few weeks, there also should be frequent "check-ins" between the worker and his supervisor to ensure that all is going well.

When a co-worker returns to work, welcome him back, include him in office activities, offer to help, or take him to lunch. In general, treat him as you would a new employee or as you would want to be treated if you returned to work from an illness.

"Why do we plan to continue our AIDS Awareness Program? For several reasons: Because we have new employees who are uneducated about HIV disease. Because our employees' family members - particularly young people - are at risk and uneducated about HIV disease. Because despite our best efforts, there remains a residue of ignorance and prejudice about HIV disease in our employee population. And finally, because all too often another Polaroid member with HIV disease calls our AIDS Program office."

Joseph G. Parham Senior Vice President, Human Resources Polaroid Corporation.

AT HOME OR AT THE HOSPITAL

- Offer support as you would any other co-worker or friend with an illness who is at home or in the hospital.
- If your co-worker is at home or working at home, call and say hello.
- Your co-worker can work at home and through the internet, faxes, and Email participate in work group activities, even attending meetings through conference calling.
- Simply send a card, flowers, or a balloon that says, "I care."
- Call and ask if it's convenient before you go visit. Your co-worker may not feel up to a visitor that day. Don't be afraid to call back and visit on another occasion.
- "Office gossip" can be healthy. Keep your co-worker in touch with "the news" at your workplace.
- Send photos or videos of people in your co-worker's work group.
- Arrange to have your workplace's newsletter sent to your co-worker's home or hospital.
- In some workplaces, co-workers have donated vacation days to a pool for people with HIV disease, so that they can use these when their sick days run out.
- When appropriate, a group of co-workers can become a caregiving team for a co-worker with HIV disease.
- If you feel comfortable doing so, check in with your co-worker's spouse, partner, or caregiver. Though it is your co-worker who has HIV disease, his caregivers may need support too. Offer your help to them, as well. They may want a break; you visit, for example, while they take some time for themselves. Or they may need someone to talk to someone who will understand.
- Help your co-worker stay connected to work and, to the extent reasonable, to continue to work. People with serious illnesses tend to recover faster and to stay healthier longer if they have a sense of purpose, such as continuing to do valued work. There are ways you can help your co-worker do work at home, such as bringing work to her.
- Many workplaces have special events such as picnics, parties, and celebrations. Offer to join your co-workers at, or even drive him, to these events.
- Offer transportation. One of the biggest problems that people with HIV disease have who are at home is getting transportation to the doctor's office, health care facilities, food shopping, drug stores, and other places, including entertainment. Don't wait to be asked, offer a ride.
- There are many other ways to be supportive. Put your common sense and creativity to work. For example, offer to do errands, cook and deliver meals, or take his pet for walks.

"Having my co-workers
educated about AIDS makes
it easier for me to talk about
my having the disease and
easier for them to listen. This
openness and honesty has
deepened our relationships."

Robert McBride Benefits Design Analyst The Gillette Company "It was a big weight off my shoulders when I told my supervisor that my brother was dying of AIDS. The caring and support that was extended to me was tremendous. It's very important for employees to know that their supervisors and co-workers do care and will lend support if given the chance. I was scared to open up about my brother's illness, but I'm glad I did, for me and for my brother."

Mary Ann Barrucci Senior Administrative Secretary Polaroid Corporation

How You Can Respond to a Co-worker Who is a Caregiver

Many of your co-workers are caring for someone with HIV disease. The person with the disease could be a member of their family such as a child, a parent, a grandchild, a brother or sister, a partner or a friend. You may not know about these co-workers because they are often frightened to tell others that there is someone in their lives with HIV disease. Many are fearful, embarrassed, and ashamed when they need not be, and they often bear the burden of the care alone when most co-workers would be more than willing to be supportive. You can help share the burden.

- You can help create a safe, accepting environment in your workplace for your co-workers affected by HIV disease by talking in a general way about HIV disease and by expressing your support for people who are affected. If your co-workers know that they will be accepted and supported, then they will be more willing to share their experiences with you and other co-workers.
- A co-worker may tell you that she is caring for someone with HIV disease. Respond with your heart. Offer help. Do not tell anyone else unless she gives you permission to do so.
- When you know that a co-worker is caring for someone with HIV disease, you are likely to want to ask how his loved one is doing. This says you care. However, your co-worker may not want to answer this question too frequently. Try not to ask the question too often. Also, be sure to ask from time to time how your co-worker is doing. This says you know the experience is affecting him as well, and he may need someone like you, who cares, to talk about it.
- Caregivers are often torn between wanting to do a good job and the demands of providing care. The caregiving may mean that she is late for work or has to leave early or during the workday. Most workplaces do not have policies that allow caregivers this kind of flexibility, but many workplaces make informal arrangements. Encourage your co-worker to find out about your workplace's policy or practices. You can help by assisting with some of your co-worker's tasks or filling in for her from time to time. You also can help by offering to provide some of the caregiving. In addition, some communities have support groups for caregivers.
- Caregivers often overlook their own needs. Encourage your co-worker to learn about and to utilize appropriate services. These services can relieve the stress on the caregiver and sometimes even improve the support given to the person in their lives with HIV disease.

OTHER WAYS TO HELP — TAKE ACTION!

- Educate yourself about HIV disease.
- Encourage your workplace to begin or to continue an AIDS education program.
- Volunteer: many AIDS service programs need volunteers. Lend a hand!
- Promote AIDS education: for your family members and friends, in your community, in schools, and in places of worship. The epidemic is growing: 100 to 200 people become infected with HIV every day in the United States. Our only way to control the epidemic now is through education.
- Educate your family about AIDS/HIV disease yourself, particularly teens and young adults. Over 70% of teens are having sex and over half of all cases of AIDS in the U.S. are among people under 25. Research shows that young people whose parents have talked with them about HIV disease tend to adopt safer sex practices. There are brochures and videos, specifically for parents and for young adults to help with these conversations (see CDC National Prevention Information Network, page 18).
- Organize or participate in a fundraising event for AIDS services or make a personal donation. Many workplaces have matching gift programs whereby the company will match your donation to a non-profit organization.
- Encourage your workplace to make contributions of money or your company's product(s) to AIDS service organizations.

COMMONLY ASKED QUESTIONS ABOUT HIV DISEASE

- Is HIV disease at work a risk?
 - No. Under normal workplace circumstances, you cannot "catch" the AIDS virus from a co-worker. HIV cannot be passed by casual contact the kind of contact you have with people at work. For example, you cannot "catch the AIDS virus" by shaking hands or sharing tools. The virus is passed through sex and other forms of direct blood to blood contact.
- Is it safe to share equipment and facilities or to eat with a person who has HIV disease? Yes. The HIV virus cannot be spread by:
 - working alongside someone with HIV disease;
 - sharing office equipment: telephones, typewriters, machines, or drinking fountains;
 - sharing restroom facilities: you cannot get HIV from a toilet, urinal sink, or towel;
 - sharing food or tableware: HIV is not transmitted by sharing food, eating utensils, or dishes;
 - shaking hands, touching, hugging, or kissing someone with HIV disease; or

"The Gillette Company realizes the great need for workplace AIDS education.
Education creates a comfortable work environment for both our employees with HIV disease and for those who are affected. Freed of fear, they can continue to be effective and productive employees."

William Donovan Former Vice President, Director of Personnel The Gillette Company ■ playing sports or exercising with someone with HIV: even if the person is sweating, the virus cannot be transmitted this way.

According to the U.S. Surgeon General, "AIDS is NOT spread by common everyday contact."

■ Should people with HIV disease continue to work?

Yes. People with illnesses, such as HIV disease, tend to live longer, healthier lives if they continue to work. Other important goals for continuing work are to maintain income level and health care benefits. For workplaces, people with HIV disease often become even better workers, because work becomes even more important to them as a source of satisfaction and hope. And keeping an experienced, skilled employee is an asset; when that person is able to continue working the workplace saves the costs of recruiting and training a new, less experienced worker.

■ Are there laws that protect workers with AIDS/HIV disease?

Yes. Two national laws (the Rehabilitation Act of 1973 and the Americans with Disabilities Act or A.D.A.) prohibit discrimination in hiring, employment, and termination against people with, or perceived to have, HIV disease. Many states have similar laws. In general, an individual cannot be refused employment or terminated solely on the basis of his or her having HIV disease. Discrimination also is prohibited in recruitment, promotion, training, lay-off, compensation, job assignments, leave, and benefits. In addition, the A.D.A. requires employers with 15 or more employees to provide reasonable work accommodations for people with disabilities, including people with HIV disease, so that they can perform the essential functions of a job. Examples of work accommodations are flexible work schedules, additional rest breaks, special equipment, or working at home. Employers are only required to provide work accommodations to people who identify themselves to their employers as having a disability.

■ Is there a test for AIDS?

There are tests to determine if a person has been infected with HIV. If you or someone else wants to be tested for HIV infection, there are a variety of ways to be tested. Ask your physician or consult your workplace health service. There are also community health providers which offer HIV testing. These services are confidential but not anonymous. There are also testing sites that provide confidential and anonymous service. For information on local test sites, check with your local AIDS organizations, public health department, or call the National AIDS Hotline (1-800-342-AIDS) for local referrals.

■ Is there a cure for HIV disease?

Not yet. However, many research efforts are currently underway to prevent infection with, to slow the development of, and to cure HIV disease. In addition, there are ever improving treatments for the infections with which people with HIV disease become ill, as well as treatments to slow the multiplication of HIV in the body and allow a person's immune system to recover strength.

■ Are caregivers at risk when providing care for their loved ones with HIV disease?

No. A caregiver can not "catch" HIV from the person to whom he is providing care, even when he provides such "intimate" care as feeding the person, bathing the person, and changing bandages and other dressings. Naturally precautions should be taken to avoid direct contact with the person's blood or when giving intravenous needle injections. These are the same precautions that should be taken regardless of the illness that a person has.

Unfortunately, a few people believe that they could "catch" HIV from a caregiver. This is not possible through the kind of everyday, casual contact that we normally have in the workplace.

GLOSSARY

AIDS (Acquired Immune Deficiency Syndrome) — a virus (HIV) that attacks the body's immune system and weakens the body's ability to fight infections causes AIDS. To be labeled as having AIDS, an individual must be infected with HIV, have a low white blood cell count (T4 cells), and have one or more of a set list of other serious infections or disease, like a particular kind of pneumonia or a special kind of cancer. AIDS is the third phase of HIV disease. The first two are HIV positive, asymptomatic and HIV positive, symptomatic.

HIV (Human Immunodeficiency Virus) — HIV is the virus that causes AIDS/HIV disease. HIV attacks and kills a special kind of white blood cell in the immune system, called T4 cells. The more T4 cells destroyed by HIV, the less able the body is to fight infections.

HIV Infection — This means that a person is infected with HIV. This does not necessarily mean that a person has been diagnosed with AIDS; the person may be in any of the three phases of HIV disease.

CD4, CD4-T cells, or T4 cells — HIV attacks and destroys special white blood cells in the immune system called T4 cells. Most people have about 800 to 1,000 T4 cells per milliliter of blood. HIV gradually destroys more T4 cells over time. The more cells destroyed, the weaker the immune system becomes, making the person more vulnerable to other illnesses. One indication that a person can be diagnosed with AIDS is that his/her T4 cell or CD4-T cell count is below 200 cells per milliliter of blood.

AIDS Test, HIV Test, or HIV Antibody Test — These are all terms used to refer to the blood test to see if a person is infected with HIV. If a person has a positive HIV antibody test, he or she may be HIV positive and may be infected with HIV. If a person has a negative test, he or she may be HIV negative and may not be infected with HIV.

RESOURCES

You and workers living with HIV disease are not alone. There are resources available to you in the communities in which you work and live and often within your own workplace. Listed below are some of the national resources available to you and your co-workers, and they can help you find local resources:

National Resources

Business and Labor Resource Service

U.S. Centers for Disease Control and Prevention - National Prevention Information Network AIDS in the workplace information, publications, referrals and resources.

Toll free: 1-800-458-5231

TTY/Hearing impaired: 1-800-243-7012

International: 1-301-562-1098

Fax: 1-888-282-7681

Email: hivatwork@cdcnpin.org
Web site: www.hivatwork.org

Hemophilia and AIDS/HIV Network

Toll free: 1-800-42-HANDI

National AIDS Fund

Workplace AIDS education materials, resources, and consultation.

Phone: (202) 408-1818 Email: aidsfund.org

National AIDS Hotlines

U.S. Centers for Disease Control and Prevention

Toll free: 1-800-342-AIDS (English)
Toll free: 1-800-344-7432 (Spanish)

TTY/Hearing impaired: 1-800-243-7889

National Association of People with AIDS

Phone: 202-898-0414

Office of Minority Health Resource Center

Toll free: 1-800-444-6472 (English & Spanish)

TTY: 1-301-589-0951 Fax number: 1-301-589-0889

Web site: http://www.omhrc.gov

State Resources

Most state public health departments have AIDS information offices and hotlines, including information on where to get tested for HIV. Most local areas have community AIDS prevention and education services. See telephone listings.

Most Red Cross chapters have AIDS/HIV disease resources. See local telephone listings or call the National Headquarters of the American Red Cross (703) 206-7120.

Your Workplace

Many workplaces have AIDS resources. Consult your workplace's Human Resource, health services, legal, benefits, Employee Assistance Program personnel or your supervisor to find out what AIDS resources your workplace has. Your workplace also may have a list of local community resources.

Internet

aegis.com – largest collection of HIV-related documents in the world.

hivinsite.ucsf.edu – comprehensive glossary of medical terms; state-by-state statistics and hotlines.

theBody.com – excellent general source of information, opportunity to pose questions about workplace issues that will be answered by specialists in the field.

ama-assoc.org – Journal of the American Medical Association site; comprehensive collection of journal articles and studies.

ytsyn.com – New York Times syndicate AIDS News: HIV-related stories in the New York Times going back at least one year.

healthfinder.gov – CDC sponsored site that directs people to health information sites that are reliable and well-documented.

workforceonline.com – best source of workplace-related information for HR professionals; this journal addresses HIV issues more often that nay other publication for HR professionals.

RECOMMENDED READINGS

A few suggestions in this guide were inspired by or borrowed from the following:

When A Friend has AIDS. Chelsea Psychotherapy Associates New York.

Taking Care of Business: AIDS in the Workplace, Corporate Program Planning Guide and Supervisor's Guide. R.F.J. Williams, Ph.D., et. al; New England Corporate Consortium for AIDS Education.

AIDS and the Workplace: A Guide for Employees. Polaroid Corporation.

AIDS Family Guide. San Francisco AIDS Foundation.

Caring for Someone with AIDS. US Department of Health and Human Services.

The Next Step: HIV in the 90's, A Management Guide to AIDS in the Workplace. San Francisco AIDS Foundation.

Other readings:

The Caregivers' Journey: When You Love Someone with AIDS, Mel Pohl, M.D., Deniston Kay, Ph.D., and Doug Toft. HarperCollins Publisher, 1990.

Caregiver Secrets. Healthwise, Bosie, Idaho.

Saying Goodbye to Someone You Love. Chelsea Psychotherapy Associates, NY, 1988.

When Someone Dies. (Planning guide for caregivers.) Impact AIDS, 1993.

Coping with Grief. San Francisco AIDS Foundation, 1989.

On Death and Dying. Elisabeth Kubler-Ross. MacMillan Books, 1970.

To Live Until We Say Goodbye. Elisabeth Kubler-Ross. Prentice hall, 1980.

Grief in the Workplace: When a Co-worker is Ill or Dies. Hospice Council of Metropolitan Washington.

Grief in the Workplace: A Guide for Managers. Hospice Council of Metropolitan Washington.

A Guide to Grief. Hospice Council of Metropolitan Washington.

For additional copies of this guide (When a Co-worker is Living with AIDS/HIV Disease), contact:

Business and Labor Resource Service

U.S. Centers for Disease Control and Prevention

Toll free: 1-800-458-5231

Email: hivatwork@cdcnpin.org
Web site: www.hivatwork.org

